

# Death or dialysis: the value of burdensome life-extending treatments for the cognitively impaired

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## Abstract

All medical treatments carry with them some level of burden for the patient, though this is usually outweighed by the benefits. Some long-term, life-extending treatments, however, are highly burdensome and the benefits are not always clearly greater. When a patient lacks decision-making capacity, there is a risk of undue harm if the decision is made on their behalf to initiate that treatment. In this chapter, I question the prioritisation of life-extension over quality of life in such circumstances, arguing that the latter ought sometimes to be prioritised. I suggest that in appealing to the principle of equal treatment of the cognitively impaired (which is endorsed in the majority of countries and is often the very purpose of legislation which governs treatment decisions for this population) we ought to accept that the very fact some patients with decision-making capacity choose to forego a medical intervention entails that sometimes cognitively impaired patients in similar situations ought also to forego that medical intervention. In doing so, maintenance dialysis is employed as a case study.

Kidney failure is a reality for millions of individuals globally. Due to the shortage of organs for transplantation, patients with or approaching kidney failure are usually started on maintenance dialysis. This is often considered the default, with the alternative of conservative kidney management – which, incidentally, some studies have suggested may provide a similar survival benefit in some patients – thought of as giving up. Dialysis is a hugely burdensome treatment, often proving both physically and mentally exhausting and thereby negatively impacting on quality of life. Depending on treatment modality it may also require thrice weekly visits to an outpatient unit for the procedure to be performed. With the increasing age of the dialysis population, for patients to have several comorbidities is common and may compromise quality of life further. Given the significance of these burdens, it is not uncommon for patients – particularly those who are older and with several comorbidities – to forego dialysis in favour of conservative kidney management.

Many of the burdens associated with dialysis may be exacerbated in cognitively impaired patients; they may not understand why they are being put through the treatment, and dialysis clinics may not be suitable environments depending on the nature of the patient's impairment. Not only are the burdens high for cognitively impaired patients, but these patients may be subjected to them for an extended period of time. The organ shortage, as well as many older cognitively impaired patients not being suitable candidates for transplantation, mean that dialysis is not always a bridge therapy. Rather, it is something that will be a part of the rest of these patients' lives. This raises the question of dialysis withdrawal, which I frame in terms of the equivalence thesis and the possible omission bias of clinicians.

I conclude that given some patients choose themselves to forego dialysis, patients who lack decision-making capacity ought sometimes also to forego dialysis in favour of conservative kidney management. This discussion is applicable to other highly burdensome treatments for cognitively impaired patients, and indeed is also useful in considering decisions concerning dialysis more broadly. Nonetheless, I also call for further research in this area to better explore the issues raised.

Keywords: Dialysis, Conservative kidney management, Kidney failure, Cognitive impairment, Dementia, Ethics

## 1 Introduction

All medical interventions entail some level of burden to the patient, whether as trivial as the inconvenience of adhering to a course of antibiotics or as significant as the lengthy recovery time following major surgery. These burdens are usually justified on the basis of being outweighed by the benefits of the intervention which, in general, means the curing of the patient's ailment or at least the relief of symptoms. Some interventions, however, are not so clearly justified on this basis; sometimes the burdens seem equal to – perhaps even greater than – the benefits. Providing treatments with apparently greater burden than benefit is not ethically problematic if the patient has provided properly informed consent following discussion of available options.<sup>1</sup> However, where a patient lacks decision-making capacity<sup>2</sup> there is a risk of them being significantly burdened without sufficient benefit-related justification.

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<sup>1</sup> In the interests of patient autonomy, patients have a right to make what may seem to an observer to be bad decisions. There is disagreement as to the limits of this right, but that is beyond the scope of this chapter.

<sup>2</sup> Use of the term 'decision-making capacity' in this chapter refers to a patient's lack of decision-making capacity specifically in relation to the decision as to whether to initiate

In this chapter, my focus is long-term, life-extending medical interventions which are recognised as highly burdensome. As a case study, I will discuss the value of maintenance dialysis for adult patients with or approaching kidney failure<sup>3</sup> who lack decision-making capacity. This is a pertinent example given the extent of the burden dialysis entails; it is an intervention which continues on a regular basis for decades in many cases, and, for most, until death.

The starting point of this discussion is that a decision as to the initiation of dialysis for a cognitively impaired patient must be made, and must be made in that patient's best interests.<sup>4</sup> Of course, it is possible that such a patient will have previously formally expressed views which a doctor is unsure as to whether to respect. There may be concerns over when the views were expressed or what information they were based on (Conneen *et al.*, 1998; Scott *et al.*, 2018). This represents a voluminous discussion in its own right and will not, therefore, be discussed here. Rather, it will be assumed that no such views have been previously expressed by the patient.<sup>5</sup>

It is not my intention in this chapter to provide an answer as to whether a cognitively impaired patient should be started on dialysis. Indeed, I do not believe it is appropriate to seek such a blanket solution since decisions of this nature will be highly individualised to each patient.<sup>6</sup> Instead, I will demonstrate that cognitively impaired patients should *sometimes* forego dialysis through a discussion of quality of life concerns and the role of dialysis as a bridge therapy. This will appeal to the principle of equal access to healthcare for the cognitively impaired. First, though, I will provide some background to kidney failure and its treatment.

For patients with or approaching kidney failure, there are few options: transplantation, dialysis, or conservative kidney management (CKM). The pre-

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maintenance dialysis. Decision-making capacity is decision specific so a patient who lacks the capacity to consent to dialysis may still be able to make other decisions about their care and/or non-health matters.

<sup>3</sup> Chronic kidney disease is considered to become kidney failure when it reaches Stage 5, which is the point at which the patient's estimated glomerular filtration rate drops below 15ml/min/1.73m<sup>2</sup> (National Institute for Health and Care Excellence, 2015).

<sup>4</sup> The term 'best interests' has a specific legal meaning in some countries – notably in England and Wales where it is an important element of the Mental Capacity Act 2005. The use of the term in this chapter, whilst inevitably bearing similarities to this legal meaning, is more general and ethical and should not be interpreted strictly in line with the Mental Capacity Act 2005 usage or that of any other legislation.

<sup>5</sup> It is, of course, preferable for there to be previously expressed preferences of the patient to guide the decision-making process. As such, patients who can ought to be encouraged to make views and preferences known as early as possible (meaning upon being diagnosed with chronic kidney disease) in case they later lose cognitive function. That way supported decision making is more likely to be feasible which is preferable in terms of respect for autonomy to any form of substitute/proxy decision maker.

<sup>6</sup> For further discussion of the individualised nature of medical decisions in relation to wider obligations to society, see the chapter in this volume by Alex.

ferred option is a kidney transplant, though the global shortage of organs for transplantation means that this is often not an option. Even if a patient is likely to receive a transplant, waiting lists are usually several years. It is therefore common for patients to dialyze as a bridge therapy when the long-term plan for their care is a transplant, essentially leaving two choices for most patients with or approaching kidney failure: dialysis or CKM.

There are several dialysis modalities. The more traditional haemodialysis requires a patient to sit for a period of four hours, three times a week, connected to a dialysis machine through an arteriovenous fistula or other type of vascular access. This can be done at home, though it more often requires attendance at an outpatient unit. Peritoneal dialysis, on the other hand, is usually done at home. Dialysate is left in the abdominal cavity for a period of time before it is drained, and this is usually done several times daily or can be done by machine overnight. As it does not require the patient to frequent a dialysis centre, peritoneal dialysis is generally considered to allow greater independence and may, therefore, be best suited to patients who are more active.

The alternative, non-dialytic pathway is CKM. The intention of CKM is to ease symptoms and, at least to some extent, preserve kidney function. Many elements of CKM, such as dietary changes and medications, are also part of the care of a patient who is receiving dialysis; indeed, both options are much the same aside from the dialysis itself. CKM is not intended as a long-term option, but rather as end-of-life care. For patients who choose to forego dialysis, CKM will generally provide several months of life (O'Connor and Kumar, 2012), though this can be considerably less depending on the patient's situation. It is, therefore, an option mostly chosen by patients who are elderly and/or have severe comorbidities.

Among chronic kidney disease (CKD) patients, cognitive impairment is more prevalent than in those with normal kidney function. This is especially true of those who have progressed as far as Stage 3 of five (Torres *et al.*, 2017). Studies have also shown that cognitive function declines more rapidly in CKD patients (Findlay *et al.*, 2019), which is likely a result of the high burden of vascular disease. As such, more than 30% of patients established on dialysis have severe cognitive impairment (Ying *et al.*, 2014).

What makes this particular discussion necessary is the concern that some nephrologists favour dialysis to too great an extent (Jha *et al.*, 2017). Of course, the reverse will be true for some, as found by the Conservative Kidney Management Assessment of Practice Patterns Study (Roderick *et al.*, 2015). This is equally problematic, though it is more often reported that dialysis is overused than underused. The combination of the availability of dialysis and the technological imperative<sup>7</sup> is causing the overuse of dialysis, and arguably a loss of

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<sup>7</sup> There are several conceptions of the technological imperative. Its use in this chapter relates to Fuchs' definition as "giving the best care that is technically possible" (Fuchs,

focus on patients' quality of life in favour of length of life (Ying *et al.*, 2014). Favouring one care option is not itself problematic, but it has been found to negatively affect the decision-making process. Kaufman and colleagues have reported that some patients feel dialysis was not a choice they made, but it just "happened" (Kaufman *et al.*, 2006, p. S180). These patients had decision-making capacity and still found themselves on dialysis almost as a matter of procedure, so for patients who are unable to consent there is a risk that dialysis will be initiated when it is not clearly appropriate.

To avoid confusion, it is worth noting that I am concerned only with *maintenance* dialysis<sup>8</sup> for *adult* patients. Thus, any use of 'dialysis' should be read as 'maintenance dialysis', and 'patient(s)' as 'adult patient(s)'. Maintenance dialysis for children raises further value questions, as does acute dialysis for any patient. Whilst this discussion will certainly apply to some aspects of these other decisions, they differ in ways too significant to discuss here.

Further, I am concerned only with *permanently* cognitively impaired patients.<sup>9</sup> In the context of maintenance dialysis, as opposed to emergency dialysis, there is rarely an urgency to decisions; the condition of a patient is unlikely to decline with such a pace that an immediate decision is necessary. Therefore, if a patient has fluctuating decision-making capacity, it would generally be appropriate to delay the decision – within reason and clinical feasibility – to allow the patient to make the decision. If it is necessary that the decision to initiate dialysis be made in the best interests of a patient with fluctuating decision-making capacity, that patient may regain decision-making capacity and at that point choose to withdraw dialysis. This is important as decision-making capacity is decision specific (MacPhail *et al.*, 2015), so the inability of a patient to consent to the initiation of dialysis does not necessarily preclude that same patient from consenting to the later withdrawal of dialysis.

## 2 Quality of life

Quality of life is a common thread to discussions of the value of medical interventions. In health economics, it has long been a guiding principle in assessing the cost-effectiveness of treatments (MacKillop and Sheard, 2018). The approp-

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1968, p. 192). This is taken to mean extending life if possible – an attitude of "I can, so I should". This is, of course, partially attributable to societal pressures.

<sup>8</sup> As opposed to emergency dialysis for the treatment of acute kidney disease. Whilst some of this discussion will be relevant to decisions concerning emergency dialysis, it is not my focus.

<sup>9</sup> Arguably, certainty as to the permanence of a patient's cognitive impairment is not always possible as patients can and do unexpectedly regain cognition. Nonetheless, for the purposes of this discussion a patient is deemed permanently cognitively impaired when there is no clinical expectation that they will regain cognition.

riateness of quality-adjusted life years (QALYs) as a measure is contested yet it continues to guide healthcare commissioning decisions.<sup>10</sup> The role of quality of life in *ethical* discussions, however, is less contentious. The burdens of an intervention have just as important a role in decision making as its benefits. It is, however, not a simple calculation as with QALYs, as it is a more nuanced consideration.

Dialysis is a burdensome intervention. Not only does it take its toll physically on the body of the patient, but it can be mentally exhausting too. For some patients (particularly those that are cognitively impaired) further physical toll may come from the need to be physically and/or chemically restrained to provide dialysis; it is not uncommon for patients on dialysis to be physically resistant (O'Dowd *et al.*, 1998).<sup>11</sup> Further, there is a social burden given the time commitment and the potential strain a patient's dialysis schedule might have on relationships with loved ones. In some cases, patients receiving haemodialysis have suffered posttraumatic stress disorder as a result of their care (Tagay *et al.*, 2007). However, it is important to note variation in the impact dialysis has on patients. For some, the burden is perceived as minimal, with the lives of many patients on dialysis being only marginally inconvenienced. It seems trite to say that all patients have different experiences of the same treatment, but this is very much the case with dialysis.

The nature and extent of the burden of dialysis can vary significantly with treatment modality. Haemodialysis is generally considered more burdensome than peritoneal dialysis due to the more frequently necessary visits to outpatient units (Li *et al.*, 2010). As earlier noted, peritoneal dialysis is more common among younger patients with kidney failure who lead active lifestyles. For patients on peritoneal dialysis, the burden is likely to lie primarily in the side-effects, such as fatigue and peritonitis (National Health Service, 2018). For those on haemodialysis,<sup>12</sup> frequent visits to an outpatient unit may prove more burdensome given dialysis-related fatigue.

Patients with kidney failure are usually on a high number of medications, in part because of comorbidities. A 2009 study found the high pill burden of patients with kidney failure to be associated with a lower quality of life (Chiu *et al.*, 2009). Indeed, the median pill burden was 19, exceeding 25 in some participants. This may increase when being treated for infections at the site of the patient's arteriovenous fistula or catheter, which are common (Nassar and Ayus, 2001).

Dialysis, then, is burdensome, at least to some extent, for all patients. For

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<sup>10</sup> See the chapters by Ubels and Mitchell in this volume for further discussion of the capability approach as an alternative.

<sup>11</sup> Dialysis patients may be noncompliant in a variety of ways, including physical resistance, missed sessions, and a failure to adhere to necessary dietary restrictions.

<sup>12</sup> Assuming they attend an outpatient unit for haemodialysis, which is most common.

those with significant comorbidities, however, the burden is often intensified. With the average age of patients on dialysis rising, comorbidities – notably hypertension – are increasingly common. A 2015 study, for example, found that 40% of (mostly older) participants with Stage 3 CKD had three or more comorbidities (Fraser *et al.*, 2015). Whilst haemodialysis can prolong life in the over-75s, it has been found that high comorbidity compromises this survival benefit. This is especially true of those with heart disease (Murtagh *et al.*, 2007). Further, patients with dementia prior to starting haemodialysis do particularly poorly, with an average time to death of 1.09 years, and 2-year survival rate of 24% compared to 66% in patients on dialysis without dementia according to a 2006 study (Rakowski *et al.*, 2006).

Some comorbidities may cause mobility issues which are especially problematic for patients undergoing haemodialysis at an outpatient unit. One such patient explained in an interview; “I’ve got an ulcerated leg, and my legs give way, and I am so frightened that I am going to fall” (Noble *et al.*, 2009, p. 86). Given the frequency of visits required for haemodialysis, mobility issues will inevitably exacerbate the burden of dialysis. This is a particular issue for patients in their eighties and nineties, for whom the combination of frequent visits and mobility issues may worsen the fatigue experienced.

Concerns have also been raised as to the suitability of the environment in which haemodialysis takes place, as it may be “dementia unfriendly” due to being an unfamiliar environment that may be noisy and busy, as well as a possible lack of continuity of staff (MacPhail *et al.*, 2015, p. 492). This is in addition to the need to tolerate invasive equipment whilst sitting still for long periods of time. Whilst this study concerned patients with dementia, the same concerns hold true for patients who are cognitively impaired in other ways.

Compared to dialysis, CKM generally has a lesser burden and resultant decrease in quality of life. This is because many burdens faced by patients on dialysis are a result of the dialysis itself. However, CKM does still carry some burdens. As earlier noted, CKM entails much the same care as that received by a patient on dialysis, the difference being the absence of dialysis. Therefore, pill burden remains an issue for conservatively managed patients. Whilst similar efforts are made in CKM to manage the symptoms, burdens associated with comorbidities will also remain. Further, the absence of dialysis means that waste products will build up in the patient’s blood which might cause other unpleasant symptoms, such as a loss of appetite (Chung *et al.*, 2011).

The most significant removal of burden associated with CKM (aside from the dialysis itself) is a notable reduction in the frequency of visits to an outpatient unit. Given the fact that an elderly patient with significant comorbidities is more likely to be on haemodialysis than peritoneal dialysis,<sup>13</sup> these visits

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<sup>13</sup> It is important to note that there is geographical variation in modality, with some countries favouring peritoneal dialysis far more than others.

represent a notable burden for such patients. Depending on the nature of an individual patient's comorbidities it is possible that frequent visits to healthcare facilities will still be necessary, but in general this burden is removed when a patient decides to forego dialysis.

CKM, then, is not a zero-burden option and can still compromise quality of life. It is, however, far less burdensome than dialysis for the average patient. This fact, as I will now discuss, is a key factor in the deliberations of some patients who have the capacity to decide for themselves.

Given the significant burden of dialysis, it is unsurprising that some patients who can decide for themselves choose to forego the treatment even though the alternative – CKM – is in essence an acceptance of death. Understanding the reasons why some patients choose death over dialysis is essential to furthering our understanding of what might be the best option for a patient who lacks decision-making capacity.

Noble and colleagues interviewed capacitous patients in the United Kingdom who chose to forego dialysis, and found commonly occurring reasons for the decision to include: the arduous nature of dialysis; difficulties attending the hospital three times each week; previous knowledge of others on dialysis; and age (Noble *et al.*, 2009). One participant, after describing having witnessed others undergo dialysis, quite definitively asserted that, to his mind, “dead better [sic]”.

Similar reasons for choosing CKM over dialysis were echoed in a 2010 systematic review which found that maintaining their current lifestyle was important to patients, with quality of life being prioritised over longevity. Patients gave reasons such as “ability to continue working, maintain a social life, or care for grandchildren” (Morton *et al.*, 2010, p. 6). Whilst in some cases these facts may simply influence treatment modality – i.e. peritoneal dialysis over haemodialysis if possible – in others they lead to the decision to forego dialysis entirely.

It is apparent that quality of life is a major factor in patients' decisions to forego dialysis. The question is, then, what this ought to mean for decisions concerning dialysis for patients who lack decision-making capacity.

### 3 Bridge therapy

Dialysis has long been a means of maintaining the kidney function of patients awaiting transplantation, acting as a bridge therapy. However, over time dialysis has become more common and is now the first-line treatment for vast numbers of patients (Vandecasteele and Tamura, 2014). It is now more of a lifelong commitment than an interim means of survival for many patients. Whether or not a patient is likely to get a transplant is, therefore, less of a factor in dialysis decisions from a clinical perspective than it once was.



Having already highlighted the ways in which dialysis might be problematic for a patient who lacks decision-making capacity – particularly in terms of potential distress – it follows that putting such a patient through dialysis for the rest of their life is a hugely significant burden. For some such patients a transplant will follow, and this might be considered as justifying the short-term (relative to the remainder of the patient's life) burden of dialysis. For the majority of patients, however, this will not be the case due to the global shortage of organs and the fact that comorbidities may preclude them being deemed good candidates for transplantation.

For those patients who initiate dialysis but for whom a transplant is not a realistic prospect, the question of dialysis discontinuation is likely to arise eventually. Indeed, the only patients for whom it would not arise are those who die whilst on dialysis. Given this, any decision to initiate dialysis when a future transplant is extremely unlikely – or potentially even guaranteed not to happen if the patient is not even deemed eligible to be added to the waiting list – must recognise that withdrawal is inevitable.

It may be more difficult to make the decision to discontinue dialysis than to not initiate it in the first place. Whilst both decisions are recognition that the patient in question is going to die, the latter may not only feel more involved from the point of view of the clinician but also prove complex when discussions must be had with the next-of-kin. Here the equivalence thesis arises. The equivalence thesis is summarised by Wilkinson and Savulescu: “Other things being equal, it is permissible to withdraw a medical treatment that a patient is receiving if it would have been permissible to withhold the same treatment (not already provided), and vice versa” (Wilkinson and Savulescu, 2014, p. 128).

According to the equivalence thesis, there is no moral difference between withholding and withdrawing dialysis assuming all else is equal. Therefore, the question of discontinuation arising ought not to be problematic as withdrawal would only become appropriate if the patient's situation had altered.<sup>14</sup> We know, however, that as much as policies and guidelines employ the equivalence thesis, in practice clinicians *do* acknowledge a difference between withholding and withdrawing (Aberegg *et al.*, 2005). This is attributable to omission bias, whereby clinicians feel that harm caused by action (withdrawal) is worse than harm caused by omission (withholding).

It is problematic if clinicians do perceive the value of continuation to be greater than that of initiation, as in the context of cognitively impaired patients this could mean that a patient remains on dialysis for a significant period of time when it is not appropriate, even if the initiation of dialysis was approp-

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<sup>14</sup> Arguably, the situation will always have altered to some extent. Indeed – speaking more broadly and not only of dialysis – the purpose of an intervention is generally to change the situation for the better.

riate when that decision was made. The harm this will cause a patient in terms of dialysis burden is disproportionate and thus unacceptable, as well as the fact that the likelihood of that patient experiencing a traumatic event will increase. The initiation of dialysis, then, ought not to act as a delay tactic so that the difficult decision becomes withdrawal rather than initiation. It is important to recognise the equivalence of dialysis withholding and withdrawal to the extent that decisions to withhold or initiate are appropriately made. Then, to dispel omission bias, in later decisions as to the withdrawal of dialysis clinicians – as well as other decision makers – ought to consider the relevance of the doctrine of double effect.

#### 4 Is dialysis worth it?

To subject a patient who cannot consent to the burden of dialysis requires serious thought. In seeking to minimise the harms caused to such a patient, it must be established that the benefits of life extension are sufficient to justify the compromised quality of life.<sup>15</sup> For a significant proportion of patients who lack decision-making capacity, I argue, there is a problematic adherence among decision makers to a vitalism mindset which surfaces in the technological imperative and omission bias.

In questioning the value of life versus death, life is usually concluded to be preferable. This is an understandable default, as not only is life something that we value but also death is irreversible. However, as the worldwide long-term euthanasia debate demonstrates, life is perhaps not something to override all other considerations. There must be a point at which a life-extending intervention is no longer appropriate. If a patient is unable to make their own care decisions, whoever is doing so on their behalf ought to recognise that allowing a patient to die *can* be in their best interests. This is generally understood as the withholding/withdrawal of treatment being in the patient's best interests rather than death itself; death is an acceptable consequence as per the doctrine of double effect.<sup>16</sup> Again, this demonstrates strong negativity surrounding death in many countries.

To conclude that it is sometimes appropriate for patients with or approaching kidney failure who lack decision-making capacity to forego dialysis in favour of CKM, two premises would have to be satisfied:

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<sup>15</sup> Even if one approaches it from the other direction, questioning whether the burdens of dialysis are sufficient to justify death, the discussion is equally pertinent.

<sup>16</sup> This can be seen in the case of *Airedale NHS Trust v Bland 1993* in the United Kingdom, in which the courts did not go so far as to say that Bland's death was in his best interests, but the withdrawal of treatment was.

- (a) Where a particular treatment decision is not uncommon among capacitous patients, that same treatment decision must sometimes be appropriate for patients in similar situations who lack decision-making capacity; and
- (b) Patients with kidney failure who have decision-making capacity sometimes choose to forego dialysis, instead opting for CKM.

I have already demonstrated (b), so will now turn my attention to (a). Premise (a) speaks to the legal requirements of many countries. The United Nations Convention on the Rights of Persons with Disabilities – currently with 163 signatories – holds that a patient who lacks decision-making capacity ought not to be disadvantaged in the provision of healthcare on the basis of their cognitive impairment (United Nations, 2006). Under the Convention, the mere fact that a patient is cognitively impaired is not grounds to, for instance, withhold treatment. In practice, this means that the purpose of decision making on behalf of a cognitively impaired patient – whatever format that may take in the relevant jurisdiction – is to provide the same care a comparable patient with no cognitive impairment would receive, rather than over- or under-treating, accounting for any known views and/or preferences of the patient in question. This is an important principle to follow, as it seeks to provide equal access to healthcare for the cognitively impaired. Just as it is unfair that such a patient receives a lower quality of care than a capacitous patient, so is it that such a patient receives a higher quality of care. It is about minimising the impact of a patient's cognitive impairment on the entire process of healthcare.

The problem comes in the previously mentioned default of survival. This basic principle of equal treatment regardless of cognitive impairment is ignored when such a patient is dialysed on the basis that living is in everyone's best interests – the technological imperative. It may also be compromised if dialysis is initiated as a default when the deciding party (or parties) is unsure of the best course of action; in Germany (Deutscher Bundestag, 2009, p. 4), as well as in several other countries, the principle of *in dubio pro vita*<sup>17</sup> demonstrates the prevalence of this vitalism mindset.<sup>18</sup>

It is important to recognise that survival is not always preferable, particularly when quality of life is significantly compromised. To action the technological imperative and keep a cognitively impaired patient alive regardless of any compromising of their quality of life is to cause unjustified harm. What I am not suggesting is that because capacitous patients do sometimes forego dialysis that we should *never* dialyze a cognitively impaired patient in case they would too have chosen to forego the intervention. To deny dialysis to the cognitively impaired on the basis of that impairment alone would not only be illegal in most countries but also entirely against the principle of equal access (naturally,

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<sup>17</sup> In cases of doubt, the preservation of life is to be favoured.

<sup>18</sup> It is also ignored if CKM is chosen *because* the patient is cognitively impaired, though this, as discussed, appears to be less of a problem.

it works both ways). Rather, a sometimes-delicate balance must be struck, accounting for the benefits and burdens of each possible course of action as well as any known views and preferences of the patient.

Prevalent in many Western countries, the duty of proportionality requires that doctors achieve care goals through the least restrictive option (Hermerén, 2012). This is important in meeting the demands of non-maleficence, as pursuing anything but the least restrictive option causes unnecessary harm to a patient. CKM is evidently the least restrictive, relative to dialysis. However, care goals vary. For an older cognitively impaired patient the goal of care may be quality of life, which may be achieved through CKM. The care goals for a younger cognitively impaired adult patient may be to allow an active lifestyle which would be better achieved by dialysis (specifically an at-home option if possible). It is, of course, possible that the care goals of a patient are broadly life extension – perhaps based on previously expressed views and preferences – and dialysis may be sought as a result. In such circumstances, however, CKM may still be appropriate depending on the potentially compromised survival benefit of dialysis when a patient has certain comorbidities.

One might argue that the decisions of capacitous patients bear no relation to decisions made on behalf of the cognitively impaired. After all, a patient deciding as to their own care may make a “bad” decision.<sup>19</sup> This is indeed true, and clinicians do have to accept that some patients make decisions which they entirely disagree with, as that is the nature of patient autonomy. It is for this reason that I suggest the fact capacitous patients sometimes forego dialysis ought to mean that patients who lack decision-making capacity ought *sometimes* not to be dialyzed. To truly adhere to the equality of care that is sought for the cognitively impaired, it is important that it reflects the care of those without impairment not only in the availability of options, but also in the decisions made.

## 5 Conclusion

Decisions concerning dialysis for cognitively impaired patients are not straightforward. A one-off operation with a short recuperation period is likely to more clearly hold value, but dialysis represents a significant long-term burden for (depending on the individual patient) little benefit. I reject the technological imperative and suggest that it can indeed be considered in the best inte-

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<sup>19</sup> Generally, there is a recognised right to make a “bad” decision afforded to patients. In the United Kingdom, for instance, the Mental Capacity Act 2005 notes that a patient cannot be deemed to lack decision-making capacity on the basis of having made a decision their clinician considers bad. It is for this reason that Jehovah’s Witnesses are permitted to refuse blood transfusions.

rests of a cognitively impaired patient to forego dialysis. Many factors are relevant to such a decision, but the fact that some patients do choose CKM suggests that upholding equality in the treatment of the cognitively impaired requires that some do not initiate dialysis.

It is important that any predisposition of clinicians in favour of dialysis does not have an impact on these decisions so that cognitively impaired patients are not subject to disproportionate harm. A tendency towards active treatment may be fuelled by many factors beyond simply the clinician's personal view – a fear of legal action from family, or perhaps business/financial reasons in some health systems – and there is, then, a potential for moral distress (Ducharlet *et al.*, 2019). This is as much an issue as a clinician's personal view guiding a decision, and where this is the case it is important that appropriate measures are put in place to allow clinicians to act in the best interests of patients without feeling constrained by external factors.

My focus has primarily been on the concern of overdialyzing, but underdialyzing is also problematic (MacPhail *et al.*, 2015). The reason for my focus on the former is that it appears to be more prevalent in the literature (Brennan *et al.*, 2017; Clement *et al.*, 2005; Ying *et al.*, 2014). However, it is important to recognise that underdialyzing the cognitively impaired is inevitably an issue *to some extent*.<sup>20</sup> As much as I have outlined reasons why it may be more appropriate for a cognitively impaired patient to begin CKM rather than dialysis, for some dialysis will clearly be the right choice.

Further, I recognise that much of the evidence discussed pertains to elderly patients. This is due to a lack of literature concerning younger adult patients, especially those with cognitive impairments. Given that patients with kidney failure are, on average, elderly, this is unsurprising. It does, however, mean that these perspectives are missing, thereby limiting the applicability of this discussion beyond elderly patients (though it still holds some relevance in a general sense).

In relation to dialysis – and likely many other treatments – further research is needed to better understand the experiences and views of the various parties involved in these complex care decisions. Only then can a more comprehensive picture of the decision-making landscape in the treatment of patients with or approaching kidney failure who lack decision-making capacity be drawn. This is important in developing appropriate guidance for clinicians to aid the decision-making process, ensuring the right decision is made for each patient on an individual basis.

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<sup>20</sup> In addition to premature fatalist outlook, clinicians may oppose dialysis for some patients for financial reasons. For instance, less complex patients may be prioritised for dialysis in a pay-for-performance system (Jha *et al.*, 2017). This issue, whilst important, has not been explored in depth as it is applicable only in some countries.

I have demonstrated that the value of dialysis for a cognitively impaired patient is far from clear. The significantly compromised quality of life – reinforced by the fact that this is a key factor in the decisions of capacitous patients to forego dialysis – brings into question the balance of benefits to harms, indicating that starting a patient who lacks decision-making capacity on dialysis might in fact go against the principle of non-maleficence. The question of value is complicated yet further when the patient is not a candidate for eventual transplantation. Where dialysis does not act as a bridge therapy, the patient is being subjected to the burden for the remainder of their life.

The purpose of this chapter has not been to provide an exhaustive discussion of the myriad ethical concerns in the care of cognitively impaired patients with kidney failure, nor a practicable ethical decision-making framework. Rather, I have outlined why dialysis might not be appropriate for a cognitively impaired patient *even if it is life-extending*. The technological imperative – as much as premature fatalism – is a barrier to appropriate care for cognitively impaired patients with or approaching kidney failure, and it is essential that clinicians recognise this and ensure decisions regarding dialysis and CKM are always in the best interests of the patient. Whilst this chapter has focused on kidney failure, parallels can certainly be drawn to decisions on behalf of patients concerning other treatments. Finally, whilst I have been concerned with cognitively impaired patients, many points bear relevance to the care of patients with or approaching kidney failure *with* decision-making capacity.

To close, it is worth briefly touching on the impact the COVID-19 pandemic has had on the issues addressed in this chapter. Whilst this chapter was written prior to the outbreak of the virus, it would be remiss of me not to mention it. First, the pandemic raises ethical issues in kidney care, in part due to the fact that some COVID-19 patients develop acute kidney injuries (Martin *et al.*, 2020; Parsons and Martin, 2020). As with ventilators, there have been concerns that there will be insufficient resources to meet the needs of both long-term patients and those with acute kidney injuries secondary to COVID-19. There is also a fear that patients who are cognitively impaired may be negatively impacted by the additional pressures placed on health systems as they are a vulnerable group (Parsons and Johal, 2020). This is not the place for a detailed discussion of how things are different in present circumstances, but it is important to recognise that they are and that they may continue to be for some time.

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